

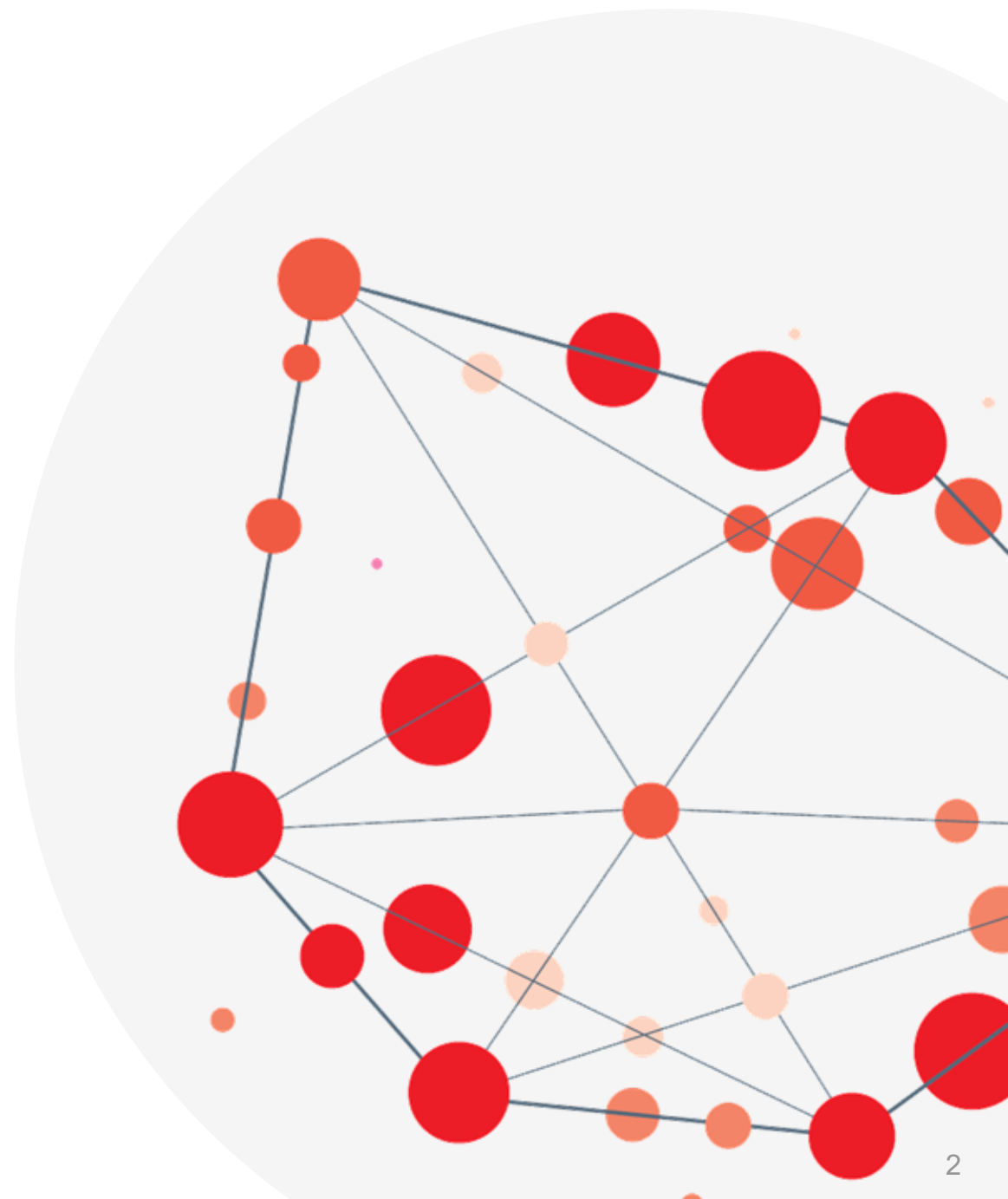


WECAN
Foundation

POLICY PLAN 2025

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Our story

An abstract geometric pattern consisting of various-sized circles and thin lines connecting some of them, creating a network-like structure. The circles and lines are in shades of gray and white, set against a dark blue background.

OUR STORY

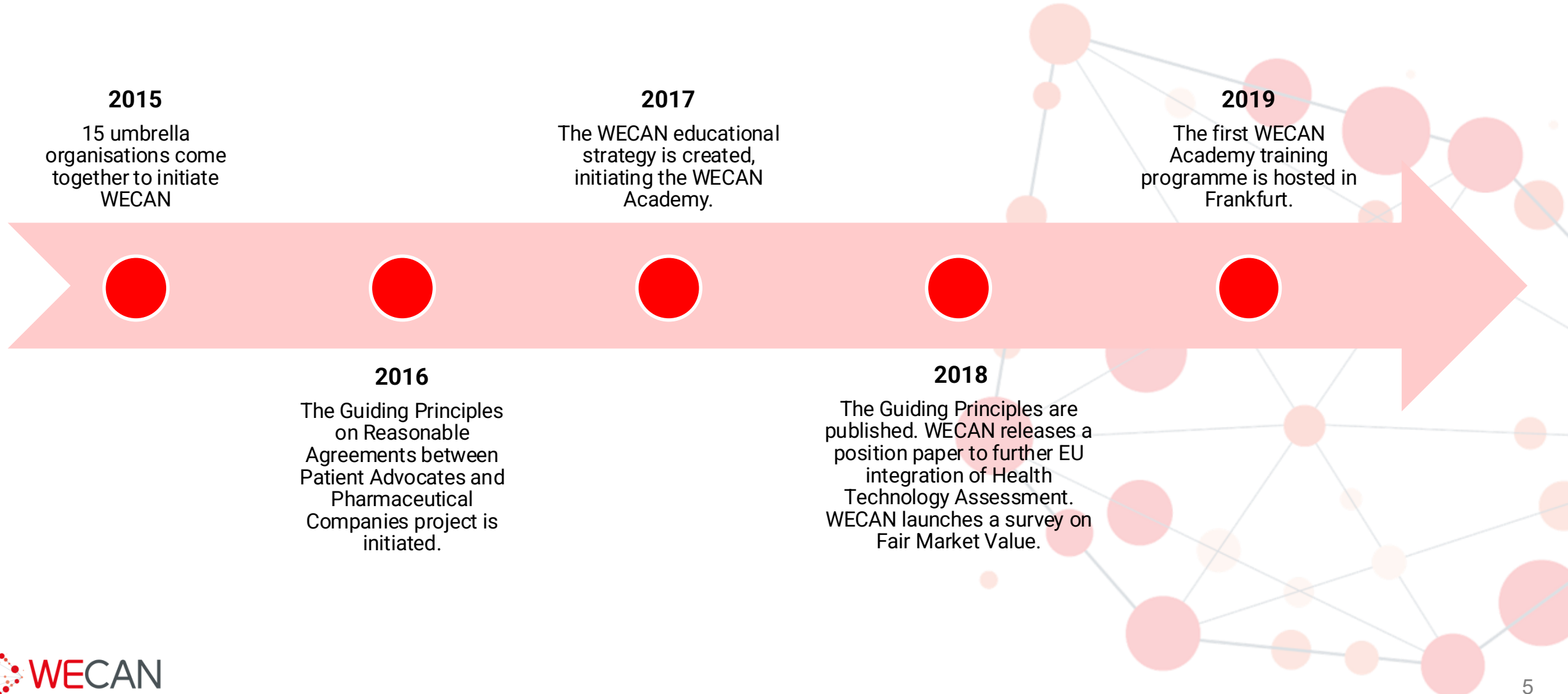
WECAN was founded in 2015 by 15 umbrella cancer patient advocacy organisations. What began as an informal network has now become the **WECAN Foundation**, officially established in 2025 to expand our reach, strengthen partnerships, and deepen collaboration with stakeholders across Europe and overseas.

With the establishment of the WECAN Foundation, we reaffirm our commitment to fostering partnerships between patient organisations and stakeholders to drive meaningful, measurable changes for the cancer community. For more information about the WECAN Foundation, please visit <https://wecanadvocate.eu/>

The WECAN Foundation focuses on collecting patient evidence and education-related advocacy initiatives for cancer patient communities.

OUR STORY

WECAN Over the Years



OUR STORY

WECAN Over the Years

2020

WECAN expands its educational workstream and Evidence-Based Advocacy: Evidence Generation and Publications is initiated as an online webinar series.

2022

The European Atlas on Clinical Trials in Cancer and Hematology, is launched. The eLearning platform expands with courses on GDPR and the Fundamentals of Evidence-Based Advocacy.

2024

During the WECAN April retreat, members decided to establish a Foundation in the Netherlands

2021

WECAN Governance document is approved by all members.

2023

The WECAN Governance document was approved by all members.
WECAN launched its WECAN Online Academy eLearning platform and open-access online training courses.

2025

Establishment of the WECAN Foundation

Mission & Values

An abstract geometric pattern consisting of various-sized circles and thin lines connecting some of them, creating a network-like structure. The circles and lines are in shades of gray and white, set against a dark blue background.

MISSION & VALUES

MISSION

Our mission is to improve the outcomes for all cancer patients by acting as a well-coordinated cancer patient community towards all stakeholders by building levels of trust, collaboration, alignment, and mutual support in the pan-European cancer patient community.

VALUES

These core values shape our mission, our decisions, and the way we work together with our community.

- Diversity and representativeness
- Transparency
- Mutual respect and respect
- Mutual support
- Principle of subsidiarity -WECAN acts in the interest of all WECAN members and will not speak on behalf of any of its members.

Statutory Objectives

STATUARY OBJECTIVES

The objectives of the Foundation are:

- to improve the outcomes for all cancer patients by acting as a well-coordinated cancer patient community towards all stakeholders, by building levels of trust, collaboration, alignment and mutual support between cancer patient umbrella organisations;
- as well as to perform all activities which in the broadest sense relate or may be conducive to the above.



Strengthen Cancer
Patient Advocacy



Increase Alignment and
Collaboration



Share Workload and
Avoid Duplication



Provide Education and
Resources

STATUARY OBJECTIVES

The Foundation attempts to achieve these objectives through, *inter alia*,

- the strengthening of collaboration between cancer patient umbrella organisations;
- the alignment on and development of projects and initiatives;
- the provision of resources and training for patient advocates and patient organisations;
- the joint action at advocacy and policy level;
- the contribution to stakeholder projects and initiatives;
- the participation in platforms, networks and consortiums;
- the procurement of grants and fundraising,
- and furthermore everything that is directly or indirectly related or beneficial to the foregoing, all in the broadest sense.

Strategy

The background is a dark blue-grey color. It features an abstract pattern of light grey dots of various sizes connected by thin, light grey lines, creating a network or molecular structure. The dots and lines are more concentrated on the right side of the image, with the word 'Strategy' positioned over the left side of this pattern.

STRATEGIC OBJECTIVES

Empower members to become stronger advocates

- Ensure WECAN members are equipped with the knowledge, tools, and guidance to engage in advocacy.
- Create opportunities for members to take meaningful advocacy actions, enhancing their confidence and capacity to influence decision-making.

Establish a Strong & United Voice

- Take collective action to ensure that cancer remains a priority on EU policy and research agendas.
- Serve as the go-to organization for European policymakers and regulatory authorities seeking patient perspectives on cancer-related policies and regulations.

Influence Research to Address Cancer Patient Needs

- Drive and shape research priorities, including PROs and PROMs, to ensure they reflect the needs and perspectives of cancer patients.
- Position WECAN Foundation as the pan-cancer EU reference organization for research initiatives that impact cancer patients.

Collaborative Action Across Members

- Facilitate joint activities and strengthen collaboration to maximize the impact of shared actions for the benefit of the cancer patient community.

WECAN Activities



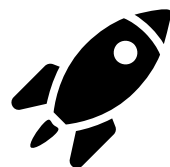
WORKSTREAMS

EDUCATION



WECAN offers patient advocates and organisations valuable programs and resources to develop their knowledge and skills.

RESEARCH



WECAN advances cancer advocacy through a research-driven approach tailored to cancer patients across all indication areas. By leveraging robust data, it ensures that evidence-based initiatives align with patients' needs and outcomes are effectively communicated to enhance engagement and maximise impact.

POLICY



WECAN enhances cancer advocacy in Europe by fostering collaboration, driving joint actions, and addressing needs through policy, research, and capacity building. These efforts aim to improve outcomes for cancer patients

PROGRAMMES AND INITIATIVES

- WECAN Academy
 - WECAN Academy 4-day in-person training
 - WECAN Academy Online training
- WECAN Evidence-Based Advocacy Programme
 - Patient Experience Data Course
 - Cancer Survey
- WECAN EuroACT

PROGRAMMES AND INITIATIVES

WECAN Academy 4-day in-person training

The WECAN Academy is a comprehensive training program designed to empower patient advocates of all levels -from novice to expert- by enhancing their understanding and skills across various areas of advocacy.

Originating as a four-day training event in 2019, the WECAN Academy has evolved to encompass a virtual training series and on-demand courses, ensuring accessibility and flexibility for participants.



One of WECAN's key objectives is to **increase the capacity and number of well-trained patient advocates and patient experts** to further grow our community of activists that can induce change.

- Cultivate competent patient advocates with knowledge and skills to engage in discussions and decision-making processes.
- Move beyond anecdotes and opinions towards evidence-based patient advocacy.
- Enable advocates to become multipliers of knowledge within and beyond their patient community and to lead on meaningful and tangible advocacy efforts

PROGRAMMES AND INITIATIVES

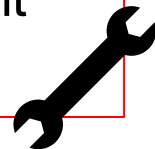
WECAN Academy 4-day in-person training



Knowledge pillars of successful cancer patient advocacy

ADVOCACY TOOLS & SKILLS

- Accessing information
- Project management
- Presentation skills
- NGO governance
- Financial management
- Managing volunteers



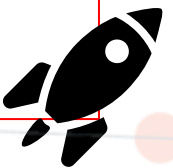
HEALTHCARE SYSTEMS, POLICY & ACCESS

- Access to treatment & care
- Regulatory processes
- Healthcare system: EU vs country level
- Patients' rights



RESEARCH & DATA

- How research & development works
- PROs
- Reading scientific papers & interpreting data
- Evidence-based advocacy



DEI

- Diversity, Equity and Inclusion (DEI) reflected in all above pillars



PROGRAMMES AND INITIATIVES

WECAN Academy Online training



Capacity-building programs in patient advocacy

WECAN's educational platform includes several free open access courses:

- Fundamentals of Evidence-Based Advocacy
- GDPR for Patient Organisations
- Patients in Publications
- Understanding the EU Clinical Trial Regulation no. 536/2014

From 2023 and in 2024, WE CAN developed on-demand educational modules to meet the needs of patient advocates across Europe and beyond, and a new course on Patient Experience Data was launched.

ONLINE Learning Platform



PROGRAMMES AND INITIATIVES

WECAN's Evidence-Based Advocacy (EBA) Programme

WECAN's educational initiatives focus on Evidence-Based Advocacy (EBA), emphasising the importance of advocating in a scientific, targeted, and professional manner while measuring advocacy impact.

Evidence-Based Advocacy means advocating in a targeted, scientific, well-educated, and professional manner to drive change. For patient advocates to effectively advocate for unmet patient needs, they must generate robust data.

Recognising the increased awareness and importance of EBA within the patient community, WECAN addresses the educational gap by providing training on how to generate and utilise data in advocacy.

Since 2020, WECAN has trained advocates to conduct evidence-generation projects and publish their findings



PROGRAMMES AND INITIATIVES

WECAN's Evidence-Based Advocacy (EBA) Programme - Patient Experience Data Course (PED)

- Patient organisations are increasingly involved in **generating data and evidence** through various means, including surveys, patient preference studies, and registries
- There is a need for **knowledge on data strategies**, which would **empower** patient organisations to take control of data initiatives and develop future funding streams for their non-profit organisations.
- Patient organisations could be trained to ensure the lawful use of data, manage consent, and oversee the dissemination of results to different stakeholders



PED aims to increase advocates ability & knowledge on developing and deploying data strategies and data business models for patient organisations

PROGRAMMES AND INITIATIVES

WECAN's Evidence-Based Advocacy (EBA) Programme - **Patient Experience Data Course (PED)**

Aggregated data could serve as a robust resource for patient advocacy, research, pharmaceutical studies, and enhancement of care

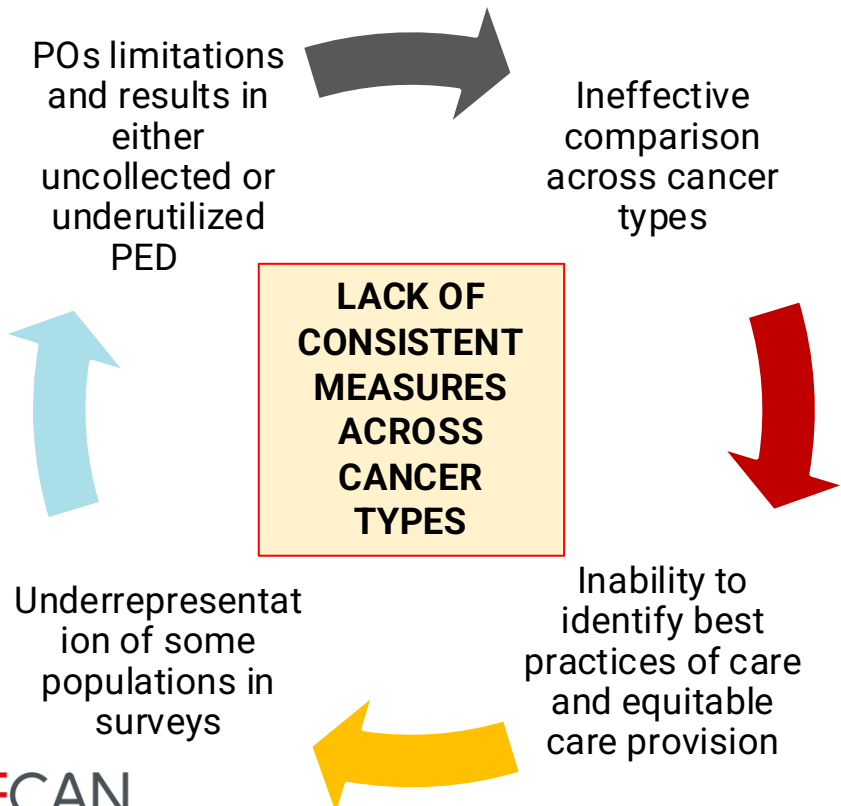
OUTCOMES

- Understand the data landscape and interests of stakeholders generating/using healthcare data
- **Understand policies on data processing, transfer, protection/security, access, governance, and common standards**
- Inform on the role and strategies for patient organisations in gathering, supervising, enabling or using data
- **Understand potential funding and income models for patient organisations in relation to data**

PROGRAMMES AND INITIATIVES

WECAN's Evidence-Based Advocacy (EBA) Programme – **Cancer Survey**

The Cancersurvey is a **cross-sectional pan-European survey** study aiming to gather and compare Patient Experience Data (PED) **on cancer patient journey**, from the moment of diagnosis to treatment, care, quality of care, communication, support, and life post-treatment, and results publication across multiple disease areas in cancer.

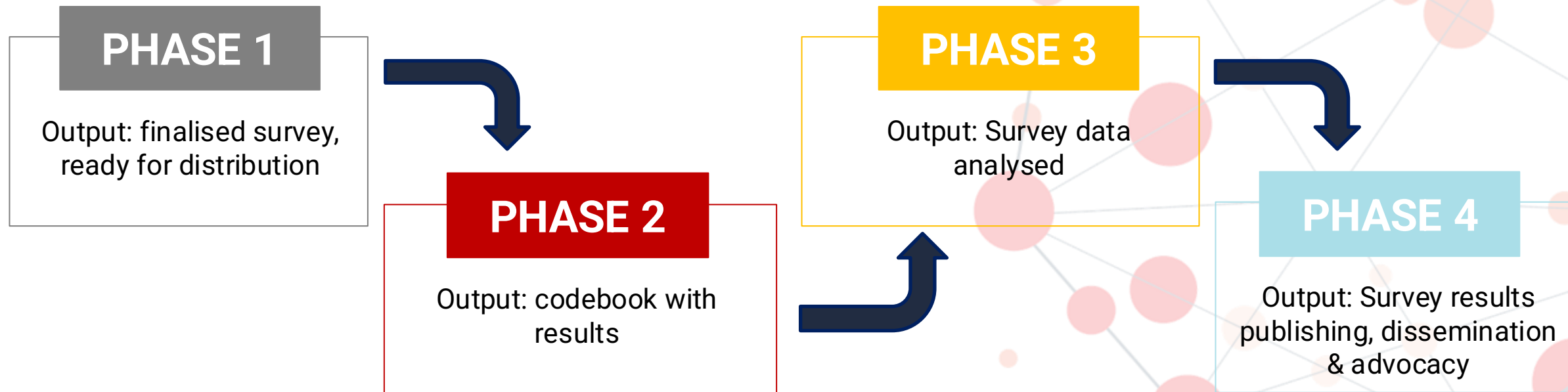


- Help providing patients with an optimal experience, and enhance their health and well-being, and advocate for it.
- Inform regulatory and payer decisions by providing robust, consistent and patient-led PED.
- Guide decisions in R&D and clinical practices during intervention creation and commercialization, bearing in mind the continuum of care.

PROGRAMMES AND INITIATIVES

WECAN's Evidence-Based Advocacy (EBA) Programme – **Cancer Survey**

The Cancersurvey is divided in 4 Phases and its objectives include developing **community and disease-specific insights** for advocacy purposes, collaboration on the project and involving representatives from WECAN member organisations in the survey development process.



PROGRAMMES AND INITIATIVES

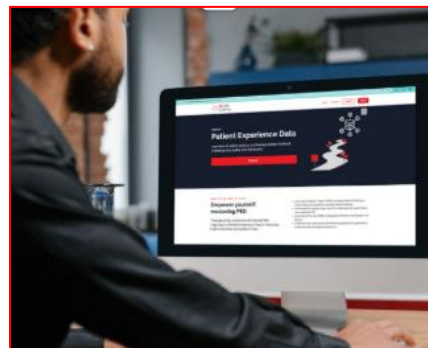
WECAN EuroACT

Rationale

Hypothesis 1. Trials are not run in all European countries, and this might cause **inequalities** in access to trials exist between regions

Hypothesis 2. When trials do take place, the collection of **Patient Reported Outcomes (PRO)** data might not always take place, and if it does, the tools (**Patient Reported Outcome Measures-PROMs**) used are not meaningful to **understand** the reality on how patients perceive the effects of a disease or its treatment

Hypothesis 3. PRO data might not be **used or published**



Objectives

1. To understand the clinical trial landscape and inequalities in research on cancer and hematology across WHO Europe and the differences between countries

2. To collect evidence on the use of PRO / quality-of-life instruments in clinical trials (endpoints, measures), and to identify patterns in PRO / HRQoL data collection, listing most and least frequently used instruments.

3. Summarise, present and use results to assess and critique current practice and trends in practice.

4. Identify gaps in knowledge and practices

5. Develop community- and disease-specific recommendations to be utilised in advocacy

PROGRAMMES AND INITIATIVES

WECAN EuroACT

Solid tumours

- Bladder Cancer
- Brain tumours
- Digestive cancers
- Kidney cancer
- Lung cancer
- Melanoma
- Pancreatic cancer
- Sarcoma
- Thyroid cancer
- Neuro-endocrine cancer
- Breast cancer
- Prostate cancer

Coverage on 27 wide diseases areas

Hematologic malignant

Chronic myeloid leukaemia
Chronic lymphocytic leukaemia
Myelodysplastic syndromes
Myeloma
Myeloproliferative neoplasms (MPNs)
Waldenström's Macroglobulinemia
Lymphomas
Acute Leukaemia

Hematologic non-malignant

Idiopathic thrombocytopenic purpura
Haemophilia
Haemochromatosis
Paroxysmal nocturnal haemoglobinuria (PNH)
Sickle cell disease
Thalassaemia
AL amyloidosis

Organizations



Organisation WECAN Foundation

ORGANIZATION WECAN FOUNDATION

BOARD OF DIRECTORS

According to Article 4 of the Statutes:

- **Composition:** The Board of Directors consists of 3–7 members, always an uneven number, as determined by the Board of Trustees.
- **Appointment:**
 - First members are named in the deed of incorporation.
 - Subsequent members are appointed by the Board of Trustees, with non-binding recommendations from the General Assembly.
- **Chair:** One member is appointed as Chair by the Board of Trustees.
- **Term & Reappointment:** Members serve one-year terms and may be reappointed in line with the Operating Rules.
- **Remuneration:** Members are not paid but may be reimbursed for reasonable expenses in line with Foundation policies.
- **Termination of Membership:** Ends upon death, dissolution (if a legal entity), resignation, dismissal (by the Board of Trustees, Board of Directors, or General Assembly), loss of appointment criteria, end of term, criminal conviction, or bankruptcy/debt restructuring.
- **Absence or Inability to Act:**
 - If some members are absent, the remaining members form a valid Board.
 - If all are absent, the Board of Trustees appoints a temporary natural person until vacancies are filled.
- **Suspension:** Members may be suspended (by the Board of Trustees, Board of Directors, or General Assembly) for up to 2 months, extendable once for up to 2 months. The member has the right to present their case with counsel. If not dismissed or extended, suspension ends automatically.

ORGANIZATION WECAN FOUNDATION

BOARD OF DIRECTORS – TASKS AND POWERS

According to Article 5 of the Statutes:

- **Management Role:** The Board of Directors manages the Foundation, focusing on its overall interests and operational organisation.
- **Delegation:** Tasks and powers may be delegated to others if clearly defined, but responsibility remains with the Board.
- **Restrictions:** The Board cannot, without prior written approval from the Board of Trustees:
 - Buy, sell, or encumber registered property.
 - Act as surety, joint debtor, guarantor, or secure third-party debts.
 - Enter into other transactions explicitly restricted by the Trustees.
- **Authority:** Even without required approvals, the Board retains formal representative authority.
- **Compliance:** The Board must follow the Operating Rules, which cannot conflict with the law or the Articles of Association.

ORGANIZATION WECAN FOUNDATION

BOARD OF DIRECTORS – DECISION MAKING

According to Article 6 of the Statutes:

- The Board of Directors shall meet when deemed appropriate by the Chair of the Board of Directors, ideally four times per year. Invitations must be sent at least one week in advance.
- **Quorum & Voting:**
 - At least half of the members must be present or represented.
 - Each member has one vote.
 - Decisions require a simple majority.
 - Tied votes are reconsidered at the next meeting and rejected if tied again.
- **Participation:** Meetings may take place in person, by phone, or via video conference, provided all members can be heard simultaneously.
- **Written Resolutions:** Decisions may also be adopted in writing, by majority vote, if no member objects to this process.
- **Records:** Minutes or a resolutions list must be kept for all meetings.
- **Conflict of Interest:** Members must abstain from decisions where they have a conflict of interest. If all members are conflicted, the Board of Trustees will decide on the matter.

ORGANIZATION WECAN FOUNDATION

BOARD OF DIRECTORS



Alex Filicevas
Chair



Anita Kienesberger
Past Chair



Ariane Weinman



Erik Briers



Gilly Spurrier



Karin Kastrati



Mark Macdonnell

ORGANIZATION WECAN FOUNDATION

BOARD OF TRUSTEES

According to Article 9 of the Statutes:

- **Composition:** The Board of Trustees consists of three to five members, always an unequal number. Only natural persons may be appointed. The General Assembly determines the number of members.
- **Appointment:**
 - Initial trustees are appointed in the deed of incorporation.
 - Subsequent appointments are made by the General Assembly.
- **Term:** Trustees serve for **three years** and may be reappointed consecutively.
- **President:**
 - Elected from among the trustees by simple majority vote.
 - Serves a three-year term, with the possibility of consecutive reappointment.
- **Termination of Membership:** Ends upon death, resignation, loss of free control of their assets, end of term, loss of appointment criteria, dismissal (by the Board of Trustees, or General Assembly), or criminal conviction.
- **Absence or Inability to Act:**
 - If some trustees are absent, the remaining members form a valid Board.
 - If all are absent, the General Assembly appoints temporary representatives until vacancies are filled.
- **Suspension:** The Board of Trustees or the General Assembly may suspend a trustee for up to two months, extendable once. The trustee must be given the opportunity to respond and seek counsel. Suspension ends automatically if not followed by dismissal or extension.
- **Remuneration:** Trustees receive no remuneration, but reasonable expenses may be reimbursed in line with Foundation policies.

ORGANIZATION WECAN FOUNDATION

BOARD OF TRUSTEES – TASKS AND POWERS

According to Article 10 of the Statutes:

- Supervises the policy of the Board of Directors and the Foundation's overall affairs.
- Provides advice to the Board of Directors
- In performing their tasks, the Board of Trustees prioritizes the Foundation's interest.
- May review the Foundation's books, records, and correspondence in consultation with the Board of Directors.
- Operates in line with the Operating Rules, which must comply with the law and Articles of Association

ORGANIZATION WECAN FOUNDATION

BOARD OF TRUSTEES – **DECISION MAKING**

According to Article 11 of the Statutes:

- Meets at least once per year, with invitations sent at least one week in advance.
- Decisions are made by simple majority, provided more than half of members are present or represented. Each member has one vote; tied votes are reconsidered at the next meeting and rejected if tied again.
- Meetings may be held in person, by phone, or by video conference, ensuring all members can communicate simultaneously.
- Written resolutions are valid if passed by majority and no member objects to this process.
- Minutes must be recorded for each meeting.
- The Chair of the Board of Directors and the Secretariat lead may attend unless objected to by a trustee.
- Trustees must avoid conflicts of interest; affected members are excluded from related decisions. If all trustees face a conflict, resolutions must still be adopted with a written justification.

ORGANIZATION WECAN FOUNDATION

BOARD OF TRUSTEES



Kathy Redmond
Chair



Jean-Yves Blay



Elizabeth Macintyre

ORGANIZATION WECAN FOUNDATION

OUR AFFILIATES

24 EUROPEAN ORGANIZATIONS

WECAN is

- A successful and committed network of 24 **umbrella** cancer patient advocacy organisations active in Europe.
- Our Affiliated Organizations represent Cancer Patients across **all indications** in order to join forces on a pan-cancer level and achieve improvements and change for each and every patient.
- A **successful network since 10 years**. Founded in 2015 and heading into a Foundation in its 10th year of existence.
- Affiliated Organizations are represented in the Foundation's **General Assembly**, which has oversight over the Foundation and acts as a strategic advisory body



ORGANIZATION WECAN FOUNDATION

OUR AFFILIATES

23 EUROPEAN ORGANIZATIONS

Leaders from pan-European cancer patient umbrella networks form WECAN.



ORGANIZATION WECAN FOUNDATION

OUR AFFILIATES

24 EUROPEAN ORGANIZATIONS

Leaders from pan-European cancer patient umbrella networks form WECAN.

- Acute Leukemia Advocates Network
- Childhood Cancer International Europe
- CLL Advocates Network
- CML Advocates Network
- Digestive Cancers Europe
- EuropaDonna
- EuropaUomo
- EURORDIS - Rare Diseases Europe
- International Brain Tumour Alliance
- International Kidney Cancer Coalition
- MDS Alliance
- MPN Advocates Network
- Myeloma Patients Europe
- Melanoma Patients Network Europe
- International Neuroendocrine Cancer Alliance
- Lung Cancer Europe
- Lymphoma Coalition
- Pancreatic Cancer Europe Network
- Sarcoma Patients Advocacy Global Network
- Thyroid Cancer Alliance
- World Bladder Cancer Patient Coalition
- Youth Cancer Europe
- World Cancer of Unknown Primary Alliance
- Hereditary Cancer Advocates Europe

Budgetary policy

BUDGETARY POLICY

FINANCIAL ADMINISTRATION AND FUNDRAISING

Budgetary management

The WECAN Secretariat present the financial plan to the Board of Directors yearly. After approval by the Board, the executive authority of the budget will be delegated to the Finance team in close cooperation with the Chair of the Board. A decision-making flow will ensure a controlling body, supported by the affiliated administrative partner.

The WECAN Secretariat takes all operational decisions to achieve the aims and objectives agreed by the Board of Directors and the General Assembly, in line with the approved budget.

On a quarterly basis the Secretariat presents a financial progress report on the budget, set goals and milestones of the WECAN Foundation which will allow for financial tracking and checks and balances.

Additional funding:

The WECAN Foundation will determine which specific needs will require additional funding every year. Funds will be allocated based upon a yearly budget approved by the Board.

The Foundation's annual budget plan approved by the Board of Directors will include a provision of funds with the necessary amount to cover external audit expenses.

BUDGETARY POLICY

ANNUAL FINANCIAL STATEMENTS & RECORDS KEEPING

Annual financial statements, as per article 13 of the Statutes

Within six months after the end of the financial year, the Board of Directors must prepare the Foundation's annual financial statements as required by the law.

As per the Operating rules, accounts are certificated by external auditors appointed by the Board of Directors. The Board of Trustees oversees the selection of the auditor or the auditing company.

The annual financial statements are adopted by the Board of Trustees and must be signed by all the members of the Board of Directors and of the Board of Trustees.

They are sent for information purposes to the General Assembly.

Records keeping, as per article 13 of the Statutes:

The Board of Directors must keep records of the Foundation's financial position and of all the Foundation's activities, and must keep the relevant books, records and other data carriers in such a way, that the Foundation's rights and obligations are at all times apparent therefrom, whereby income and expenditure can be clearly traced to their source and purpose and whereby it is clear which obligations have been assumed on behalf of the Foundation, by whom and at what moment.

Books, records and other data carriers must be retained for a period of 7 years.

Budget

The background is a dark blue-grey color. It features a complex network of thin, light-grey lines connecting various circular nodes of different sizes. Some nodes are larger and more prominent, while others are smaller and less visible. The overall effect is a sense of interconnectedness and data flow.

BUDGET 2025

INCOME	
Income Received	EUR 803,200
Academy 2025	EUR 410,000
EuroACT	EUR 240,000
PED	EUR 92,800
Cancer Survey	EUR 60,000
Income Committed (to be received)	EUR 110,600
Deferred Income	EUR 406,929
Total income	EUR 1,320,729

EXPENSE	
Academy 2025	EUR 281,864
Academy 2026	EUR 13,626
ESMO	EUR 7,755
EuroACT Phase III+V	EUR 262,374
EuroACT Phase V committed	EUR 138,943
PED	EUR 20,114
PED Committed	EUR 70,573
Cancer Survey Phase I	EUR 23,549
Cancer Survey Phase I&II	EUR 147,763
Secretariat	EUR 187,779
Total expense	EUR 1,154,340
Result	EUR 166,389

Absence of Profit

ABSENCE OF PROFIT

IN ACCORDANCE WITH **ARTICLE 3** OF THE ARTICLES OF ASSOCIATION

The Foundation does not aim to make a profit. It aims to serve the public interest and to be an institution referred to in section 5b of the Dutch State Tax Act and to be designated as such by the Dutch tax authorities.

Fundraising and procurement of grants will serve the sole purpose of enabling the foundation to carry out or expand its activities, always in line with its statutory objectives.

Any incidental surplus will be used for the public benefit objective according to article 16. No more assets are held than necessary to enable the foundation to pursue its objective and continue to meet current payment obligations.

Assignment liquidation balance

ASSIGNMENT LIQUIDATION BALANCE

AS PER **ARTICLE 15** OF THE STATUTES:

(5) The Board of Directors shall determine the appropriation of the liquidation surplus in the resolution of dissolution, which liquidation surplus will be spent on behalf of or transferred to a public benefit institution within the meaning of Article 5b paragraph 3 sub a of the Dutch State Tax Act ('Algemeen nut beogende instelling') with a similar objective as the objective of the Foundation or a foreign institution with a similar objective as the objective of the Foundation.

Thank you!

